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ABSTRACT

The summary of the comprehensive needs study of individuals with the most severe handicaps presents major findings regarding definitions, incidence, needs, and current services for the severely handicapped. It is explained that information was gathered through data file analysis, client surveys, a review of the literature, and constituency impact assessments. Among findings reviewed are that the total U.S. population with most severe handicaps is 10,067,000; that age plays a crucial role in the impact of a disabling condition; that minimal efforts have been made by local governments to eliminate barriers in public housing and facilities; that transportation needs were second only to vocational placement in perceived need; that low employment rates are related to such factors as capital disincentives and employer discrimination; and that development of a weighted case closure system, reduction of caseload size and an intensive training program were felt to facilitate serving the severely handicapped. Among program and finance options suggested are consumer-run self-help organizations and a special revenue sharing plan. A final section analyzes key policy interpretations and the implications for such services as transportation, employment, health coverage, income maintenance, and consumer involvement. (CL)

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EXECUTIVE SUMMARY

OF THE

COMPREHENSIVE NEEDS STUDY OF

INDIVIDUALS WITH THE MOST SEVERE HANDICAPS

This report is submitted to the Department
of Health, Education and Welfare
by
The Urban Institute
in fulfillment of Contract No. SRS-74-54

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INTRODUCTION

Background

As early as 1959, following the Vocational Rehabilitation Amendments of 1954, legislation had been proposed to extend the benefits of rehabilitation to persons with the most severe handicaps, even when no vocational objective was obvious. It was argued that the Vocational Rehabilitation approach (an individual plan tailored to the needs of the specific individual, with case service funds for the purchase of needed services from qualified vendors when not directly provided) had much to offer for the most severely, non-vocational oriented, handicapped. Efforts to authorize the State-Federal program to offer such services (Independent Living Rehabilitation, if you will) resulted in bills passed by the 92nd and 93rd Congress. Both of these bills were vetoed, and override efforts failed.

These proposed pieces of legislation had two major thrusts. The first was authorization of a new formula grant program to provide services to individuals with the most severe handicaps without vocational objectives. The second was to move the vocational rehabilitation program in the direction of serving more severely disabled persons with vocational potential. Hearings conducted during the legislative process produced testimony to the effect that it was not certain just what was known about provision of services to these persons and that there was possible duplication of existing authorities which could provide the needed services.

Thus, a compromise was reached by the Congress and the Administration as reflected in the provisions of Section 130 of the Rehabilitation Act of 1973 (P.L. 93-112). This compromise directed the Secretary of HEW to conduct a Comprehensive Needs Study of the most severely handicapped, reading as follows:

Sec. 130. (a) The Secretary shall conduct a comprehensive study, including research and demonstration projects, of the feasibility of methods designed (1) to prepare individuals with the most severe handicaps for entry into programs under this Act who would not otherwise be eligible to enter such programs due to the severity of their handicap, and (2) to assist individuals with the most severe handicaps who, due to age, cannot reasonably be expected to be rehabilitated for employment but for whom a program of rehabilitation could improve their ability to live independently and function normally within their family and community. Such study shall encompass the extent to which other programs administered by the Secretary do or might contribute to the objectives set forth in clauses (1) and (2) of the preceding sentence and the methods by which all such programs can be coordinated at Federal, State, and local levels with those carried out under this Act to the end that individuals with the most severe handicaps are assured of receiving the kinds of assistance necessary for them to achieve such objectives.

(b) The Secretary shall report the findings of the study, research, and demonstrations directed by subsection (a) of this section to the Congress and to the President together with such recommendations for legislative or other action as he may find desirable, not later than February 1, 1975.

The Rehabilitation Act Amendments of 1974 changed the report due date to June 30, 1975.

The authorization to carry out this Comprehensive Needs Study (CNS), including demonstration projects, provide the opportunity for documentation of the needs of the severely disabled and of the place and role of rehabilitation in meeting those needs.

Contract Award

The competitive contract procurement was won by The Urban Institute, a non-profit research organization located in Washington, D.C., dedicated to social research on domestic issues. The Project Director was Dr. Jerry Turem. They were the fiscal agent and manager of this study, along with a consortium of other firms and individuals. Included in the consortium were the following groups and directors: Berkeley Planning Associates (Dr. Frederick Collignon), Center for Independent Living (Edward Roberts), Medical College of Pennsylvania (Dr. Claire Schultz), National Rehabilitation Association (E. B. Whitten), Rehabilitation Institute of Chicago (Dr. Byron Hamilton), Tufts New England

Medical Rehabilitation Center (Dr. Carl Granger), and Workers' Disability Income Systems (Dr. Monroe Berkowitz).

In addition, the following individuals were among those consulting with the project: Emiley Lamborn, Joseph LaRocca, Dr. Edward Lowman, Dr. John Muthard, Dr. Saad Nagi, Dr. Edward Newman, and Corbett Reedy. The Council of State Administrators of Vocational Rehabilitation (CSAVR) was fully involved and especially helpful and cooperative. There were, in addition, both consumer and provider advisory groups.

The study strategy essentially addressed a few key questions: Who are the most severely handicapped individuals? How appropriate are alternative operational definitions? How many severely handicapped individuals are there? What is their situation? What are their needs? How are their needs now being met?

Study Design

These issues were addressed in a number of ways: data file analysis, client surveys, a review of the existing literature, and constituency impact assessments.

The half dozen national surveys that offer information relating to disability vary in terms of the number of households, definition of disability, and year mounted. In order to get estimates of the incidence and prevalence of severe disability, these differentials were reconciled as much as possible.

The surveys, however, do not provide much detail about the situation of the disabled individual. To remedy this lack of information, a survey was developed by The Urban Institute. The target was to be a group defined as those too severely handicapped for Vocational Rehabilitation services--persons who were not accepted for the program or whose cases were closed as not rehabilitated for reasons of severity of handicap. With the support of the Council of State Administrators of VR and the yeoman work of the VR directors and agency staff in Colorado, Connecticut,

Georgia, Idaho, Indiana, Maryland, Minnesota, New York, Ohio, Oklahome, North Carolina, and Washington, who contacted a group of these clients to get consents for the interviews, extensive data on about 900 such persons was collected.

In addition to these persons, however, there are severely handicapped persons who may never get to a State agency and represent an important group to survey. The best places to find such persons in any numbers are the Comprehensive Medical Rehabilitation Centers (CMRCs). Data on about 300 such persons were gathered from 10 CMRCs: New York University Medical Center (New York), Rancho Los Amigos Hospital (Downey, Calif.), Rehabilitation Institute of Chicago, Rehabilitation Institute (Detroit), Tufts-New England Medical Center (Boston), Spain Rehabilitation Center (Birmingham), Texas Medical Center (Houston), University of Minnesota Hospital (Minneapolis), University of Washington Hospital (Seattle), and Woodrow Wilson Rehabilitation Center (Fischersville, Virginia). Data were gathered using a special functional assessment scale developed by Dr. Carl Granger of Tufts. This procedure permits a scale of severity of impairment which is correlated with other information, permiting an assessment of severity of impairment with degree of handicap.

The review of the literature, of course, is a vital element of any study such as this. Yet the literature is incredibly large. The Medical College of Pennsylvania (MCP), with its excellent staff and computer capability, was asked to assist in screening the mass of published work. MCP developed computer-screened printouts of relevant published reports. These in turn were sent to the Center for Independent Living in Berkeley, California, which did many of the actual literature reviews on subjects ranging from architectural barriers to psychological effects of disability. Much of what has been written about the needs of the severely handicapped was reviewed.

It seemed wise to enlist the aid of the various voluntary organizations that have formed around specific disability groups to work for program development and expansion and promote public education on the problems of their group. With the assistance of the National Rehabilitation Association, two sessions were held with representatives of these voluntary agencies. At the first session, the study was explained and agency input in the form of data and position papers was solicited. The second conference addressed specific issues of how to identify the hidden disabled, how to define severity, what services might be provided, and how these needs are currently being met.

In addition to developing information on service needs of the severely handicapped, it is necessary to provide information on how these needs can be met. What programs now serve the severely handicapped? What technology exists? What do service providers in VR, sheltered workshops, rehabilitation facilities and the like see as the main incentives, disincentives, possibilities, and limits of service to this group? Who might run an independent living rehabilitation program? What alternative organizational arrangements, financial incentives, and manpower requirements are available for consideration?

The providers of services to the disabled appeared to be another source of valuable information. A mail-out survey was sent to 1000 VR agency personnel (primarily counselors), 800 facilities and workshops, and 500 various professional organizations and individuals. The survey instrument raised questions about current practices in providing services to the severely handicapped and sought opinions on changes. We received approximately 1,300 responses.

A review of programs which currently provide benefits to the severely disabled was conducted by Dr. Berkowitz, with special emphasis on HEW programs but attention to others as well. Consultants prepared papers on issues affecting

certain groups (e.g., the retarded, the mentally ill, the blind, the deaf) and special concerns such as the technology of rehabilitation.

- An analysis of the costs and benefits of various alternatives of providing VR, pre-vocational, or independent living services under different conditions to groups which may variously be defined as being covered was conducted by Dr. Collignon. As a result of these analyses of needs and service provision, a number of policy alternatives to improve and expand services were designed.

Finally, the study recommends areas for further knowledge gathering activities under R&D and evaluations and reports on the demonstration projects mounted in conjunction with the study.

SUMMARY OF MAJOR FINDINGS

Definitions

1. For this report, we have termed the residual limitation resulting from a congenital defect, disease, or injury an impairment. A person with an impairment, then, may or may not have a disability, an inability to perform some key life functions. When the disability interacts with the environment to impose impediments to the individual's goals for travel or work, for example, the individual has a handicap; that is, there are severely handicapping environments as well as impairments.

2. Severity refers to the degree of impairment, disability, or handicap. At the worst degree of severe, these three terms are virtually synonymous. Furthermore, when an impairment is mild or moderate, a disability or handicap may or may not exist.

3. An impairment can only be alleviated or remediated through devices or medical care. A disability can be remediated through training, or devices or medical care. A handicapping condition, on the other hand, can be remediated through changes in the environment, or training of the individual, or both.

4. Different persons react differently to a given impairment. Thus, similar impairments may result in different disabling or handicapping conditions. Some persons are more disabled or handicapped by a given level of impairment than others for reasons other than the impairment itself, such as motivation, age, education, family, and environmental or attitudinal barriers.

5. Disabled persons face different handicapping conditions in different areas of life. For example, some severely disabled have a relative minor

handicap with respect to transportation, whereas others are severely limited by transportation.

6. Diagnostic labels are sometimes used as proxies for disabilities or handicaps. One often hears that if a person has a condition--blindness, paraplegia, retardation--that person has a "disability" or "handicap." However, any given diagnostic label implies a range of severity. Such labels often further stereotypes about the abilities of individuals which are incorrect.

Estimates of Severely Disabled Population

1. Most data files do not contain information on handicapping conditions at all; a few focus on disability. The primary data sources useful for population estimates measure inability to work attributed to some health condition or disability. However, there is no current ongoing system for data collection on the characteristics or number of the handicapped for VR purposes.

2. A comparison of the major sources of data on the disabled population results in different estimates even when controlling for year of survey, definition of disability, severity, etc. Our estimates are based on the most methodologically sound parts of different approaches. We estimated that in 1975 there are approximately the following number of most severely handicapped persons in the United States, when severe disability is considered to be analogous to severe handicap:

Noninstitutional population	8,280,000
Under age 18	180,000
18-64	4,200,000
65 and over	3,900,000
Institutional population	1,787,000
Total U.S. population with most severe handicaps ...	10,067,000

3. In general, the severely disabled noninstitutional population are older, more female, slightly more nonwhite, less well educated, and slightly more southern, and they have more than one impairment compared to the less severely disabled.

4. The largest States have the largest absolute number of severely disabled. The most frequent disability types are musculoskeletal and cardiovasular impairments, followed by mental and nervous system disorders.

VR and the Severely Disabled

1. Persons who are defined as disabled because of their inability to work tend to be older than persons of moderate work disability and to have a variety of characteristics which suggest that the labor market does not accept them because of a combination of impairment and other factors, rather than because of the extent of their impairment. The analysis of the VR program with respect to who is accepted and rejected, and who is successfully or unsuccessfully closed reflects these same factors. Because of its vocational orientation, the VR program seems to be making conservative choices regarding acceptances. For example, about 12 percent of people in our sample who had been rejected by VR because of severity were working or had worked within 1 year of being interviewed. A much larger percentage had worked within 3 years.

2. Age plays a crucial role in the impact of a disabling condition. The older person is more likely to consider himself to have severe work disability, is less likely to be admitted to the rehabilitation program, is more likely to be identified by the rehabilitation program as severely handicapped, and if admitted, is less likely to complete the program successfully.

Special emphasis on the severely handicapped in need of rehabilitation services implies focusing on older clients. Since older clients are more difficult to place, total resources would have to be increased and resources

allocated from younger to older clients. Such a reallocation of resources would probably lower the number of rehabilitations per dollar expended.

3. The referral source plays a key role in the rehabilitation system. Those referred from welfare agencies are more likely to be rejected for services. If they are accepted, however, they are more likely to complete the program. Those referred from public and private health agencies and service organizations are also more likely to be rejected for services, and if accepted, they are less likely to successfully complete the program. Those referred from hospitals are more likely to be accepted for services but less likely to successfully complete the program. Severity of handicap is the most common reason for rejection for persons referred from all these sources.

4. Education generally makes it easier to overcome a disabling condition. The better educated are less likely to suffer severe work disability, more likely to receive services if they apply, and more likely to be successfully rehabilitated if they are accepted.

5. The probability of acceptance into the program is the same for whites and nonwhites. Nonwhites are more likely to consider themselves as having severe work disabilities and are less likely to be successfully rehabilitated after they are accepted.

6. A rehabilitant is likely to be younger, white, better educated, male, not a public assistance recipient, married and living with spouse, having dependents, living in a State with high rehabilitation expenditures per disabled individual, having competitive labor market experience, and

having only one disabling condition. The disabling condition is more likely to be speech or hearing, orthopedic, amputation, mental retardation, neoplasm, digestive disorder, or genitourinary impairment.

7. In high unemployment states, the probability of acceptance into the program is higher for females, nonwhites and older people. The probability of successful rehabilitation for all applicants if lower in high unemployment States.

8. The probability of severely handicapped being denied services is lower in those States with higher vocational rehabilitation expenditures per disabled person in the State. The implication of this finding is that two people with the same set of characteristics who apply for services would have different likelihood of admittance to the program depending upon the financial allotment to the State program.

Survey Findings

Survey of Individuals Rejected by VR

1. Our interview sample of 889 physically handicapped individuals closed from VR for severity was largely white, male, and urban, and had an average family income of almost $7,000. The most striking demographic characteristic is that half of the sample was over 50 years of age, with only 31 percent under 45 years of age.

2. Approximately half of the sample had some type of orthopedic impairment; the only other frequently occurring diagnostic type was cardiac and circulatory conditions, comprising 18 percent of the sample.

3. According to the Barthel Index, 45 percent of the surveyed population were found to be completely independent in self-care and mobility, 14 percent were slightly dependent, 30 percent were moderately dependent, and only 11 percent were severely or totally dependent. On the basis of the Barthel

Index, then, there is strikingly little evidence of overwhelming physical dependency in this sample. The same conclusion can be reached on the basis of other functional limitation items--most people closed for severity can perform almost all activities of daily living.

4. Cross-tabulations between diagnostic condition and severity revealed that there is only a minimal relationship between diagnostic labels and severity. This finding has important implications for the current RSA guidelines for determining severity.

5. The most severely disabled age group was the young, aged 16-30. Furthermore, as age increased, the percentage of respondents who were totally or severely disabled decreased. A sizeable portion of young people are actually closed for severity, while older persons appear to be closed for other reasons, such as the difficulty of job placement. This suggests that the severity closure reason is being used as a proxy for case difficulty.

6. Almost half (46 percent) of the individuals of prime working age who were functionally independent or only slightly dependent and closed by VR because of severity were either working at the time, had recent work experience, or wanted to work.

7. Further analysis of young, physically independent persons with recent work experience who were rejected due to severity showed that there was no single reason for their rejection--anticipated labor market discrimination, psychological problems, disagreement over VR's program, and scheduling problems. These factors as well as conservative judgments in placement on the part of the VR counselor, may have contributed more to closures for reasons of severity than the actual physical impairments of these individuals.

8. Sixty-eight percent of the persons surveyed had some type of equipment, such as wheelchairs, canes, or dentures. Two-thirds of the respondents

indicated that they did not currently need any further equipment. However, persons indicating some need for equipment listed on average of 1.3 types of equipment needed.

9. Social Security was the agency other than VR that was most frequently contacted by the severely handicapped, 88 percent having contacted this agency, followed by the Food Stamp program (34 percent); and Aid to Families with Dependent Children (26 percent). The benefit most frequently received from all agencies combined was cash income.

10. While one-half of the population received counseling from VR, only 29 percent received any services in addition to counseling.

11. Almost two-fifths of the population stated that they did not need any additional services; the remaining group, however, indicated an average need of three services per person. The most frequently cited service needs were vocational training (21 percent), transportation (18 percent), physical therapy (10 percent), vocational placement (25 percent), vocational counseling (14 percent), and educational costs (12 percent).

12. The youngest age group seems to have had the greatest need for services of some sort, which is consistent with their lower Barthel scores. Thus, the more dependent, the greater the need for services. Younger persons also had a heavier need for vocationally related services.

13. Types of service needs clearly differed for individuals with different degrees of dependency. Medical services are needed for the most dependent, and vocational services for those less dependent.

14. Based on the findings of this survey, it would appear that many of this group of disabled are in need of services, and that many want to work and appear capable of working but are sitting at home, often quite isolated socially. Others who are less physically able are often even more neglected,

in part due to conditions which could be changed with more careful planning for the needs of the disabled. The service and equipment needs identified are within the known ability of VR to deliver.

CMRC Survey Comparisons

1. A little over 300 patients of 10 Comprehensive Medical Rehabilitation Centers (CMRCs) were also interviewed. The CMRC and VR samples differed considerably in age distribution, the CMRC sample, having about three times as many individuals under 30 years of age as well as almost three times as many individuals over 60 years of age. Despite those important differences in the age ranges of the two groups, slightly over half of both populations are older than 50.

2. Both populations are largely male, married, white, and living with their families. The CMRC population, however, had a higher percentage of females, more individuals who were widowed or single and fewer persons who were living with their families.

3. The education level of the two populations differed markedly, with the CMRC population being considerably better educated than the persons rejected from VR. More than twice as many CMRC patients had attended college or graduate school.

4. The CMRC population was much more physically dependent, as measured by the Barthel Index. For example, 45 percent of the VR population as compared to 18 percent of the CMRC group were completely independent in self-care and mobility. Almost one-third of the CMRC group was found to be severely or totally dependent.

5. The physical needs of the CMRC sample exceeded those of the VR sample. The major physical needs included rehabilitation therapy, attendant care, and equipment.

6. The CMRC population had a higher percentage of individuals in white collar jobs and slightly more than twice as many employed as the VR population. The major reason cited by the majority of both populations for not working was physical condition, although the VR population cited this far more frequently. Finally, both groups needed similar kinds of services in order to facilitate their return to work, although the CMRC population had a higher need for medical and home care services than the VR population.

Problem Areas for the Disabled

Architectural Barriers

1. Local governments have made very limited efforts to eliminate barriers in public housing and facilities. Furthermore, a great majority of the Nation's cities have not initiated any programs designed to eliminate these barriers.

2. Public Law 90-480 appears to be weakly enforced, partly because of the language in that law which allows loopholes. Better enforcement of existing standards for a barrier-free environment and a local program which contained information on how modifications could be made are two key policy options that could be pursued.

3. According to the VR survey results, 16 percent of the sample had difficulty living in or getting in or out of their homes because of architectural barriers. The major reason the barriers were not removed related to the costs of the changes.

Geographical Mobility

1. Relatively little is known about the specific mobility patterns of the severely handicapped, although it can be inferred from various surveys that their residential mobility is considerably less than that of the general population.

2. In the VR survey, 7.8 percent moved to another area because of the availability of family assistance.

3. Generally, not enough information is available to make further conclusions about the geographical mobility of the severely disabled. Pilot projects on mobility as well as extended research into actual mobility patterns should allow for formulation of more meaningful policy options.

Transportation

1. According to the VR survey, transportation services were second only to vocational placement in perceived need. Most of the transportation needs of the sample were taken care of by friends and relatives.

2. Almost one-third of the sample of persons rejected from VR go outside once a week or less.

3. Different disability groups will need different types of transportation alternatives. For example, the needs of the blind individual are quite different from the transportation needs of a quadriplegic. Furthermore, these solutions for alternative groups will be different in terms of cost.

4. Finding solutions to transportation problems of the severely handicapped is a complex undertaking, since different types of severely handicapped require different types of transportation solutions. It is important, then, that a wide range of solutions be explored and evaluated so that the most effective national program options are developed. Among the options are paratransit, retrofitting existing programs, tax subsidies for excess transportation costs to the handicapped, and reform of existing public systems.

Employment

1. Besides the limitations placed on the severely handicapped by their impairment and their socioeconomic characteristics, a number of other factors affect their level of participation in the labor market. Some of the most

important factors are inadequate aggregate demand, capital disincentives, employer discrimination, and lack of full employment in the economy.

2. In the survey of individuals closed from VR, it was found that prior to their disability the sample worked in a wide range of professions, were industrious, and many were earning an average income. Of further interest is the fact that 12 percent of the sample had worked within a year of the date they were interviewed, including 6 percent who were employed at the time of the interview.

3. Seventy-one percent of the individuals who were currently employed had perfect Barthel scores, indicating that they were totally independent in the activities of daily livng. Closures from the program, then, seem to be based on judgments about employability rather than severity.

4. These survey results indicate that special methods may have to be developed to enhance the employment situation of the young, physically independent persons rejected. For the older population, some type of increased placement program on positions with reduced duration and intensity of work may be most appropriate. The policy options for enhancing the employment prospects of the severely handicapped cover a wide range. The alternatives include affirmative action, public sector employment, public service work programs, sheltered workshops, wage subsidies, employment quotas, and projects with industry.

Social Interaction

1. Our survey documents the fact that many severely handicapped are socially isolated and have poor self-concept.

2. The majority of their social contacts are limited to family members, with very few engaging to any significant extent in outside activities.

3. Large numbers of severely handicapped are prevented from participating in social activities by attitudinal barriers, architectural barriers, and transportation barriers.

Mentally Ill

1. The mentally ill have a high probability of being accepted into VR if they get to applicant status. They are also one of the groups which, on acceptance, has a high probability of ending up not successfully rehabilitated.

2. While the number of rehabilitated persons who are mentally ill have increased in absolute numbers, such rehabilitants have declined from 6.6% of all clients rehabilitated in 1969 to 5.5% in 1972.

3. Independent living for the mentally disabled currently is in the domain of the mental health system. If future programs for ILR include the mentally ill, separate responsibilities of the different programs and agencies must be identified. We were unable to clarify such differentiations.

Mental Retardation

1. Independent living for this group is currently the responsibility of experts in the field of services to the mentally retarded. If the mentally retarded are to be included in ILR programs, separate responsibilities of the different programs must be defined. We were unable to find any logical differentiation of roles in such a program.

2. Retardation is the primary disability in almost one-eighth of all rehabilitations. However, the severely handicapped retarded are still a minority of the retarded those treated, despite some evidence that the retarded as a group are more vocationally capable than is reflected in the current VR program.

3. The VR program could help retarded persons who are seeking jobs cope with serious problems of: 1) lack of training; 2) job discrimination;

3) difficulty in locating jobs suitable to abilities, and 4) inability to complete job application forms and procedures.

4. Policy options which address the above problems include (1) assuring availability of services; (2) developing sheltered employment in the competitive labor market rather than in special workshops; (3) having longer time periods for case carrying and services; and (4) placing greater emphasis on extended evaluation.

Blind and Visually Impaired

1. VR services are available to blind or severely visually impaired persons in every State. Notwithstanding the vastly expanded employment opportunities for the blind, agencies serving the blind must constantly devote a major protion of their efforts to job placements.

2. Foremost among the multiply handicapped who require extra and special services for their education and rehabilitation are those person who are both deaf and blind. The 1967 VR amendments authorized the establishment of a National Center for Deaf-Blind Youth and Adults which develops specialized intensive services needed to rehabilitate handicapped individuals and conducts research on the deaf-blind. It is not the state of knowledge which creates unmet needs, for this group, but the limitations in resources.

3. Little seems to be done to help the aging blind, who constitute a majority of all blind, reach a status of self-care. To attain this status they need a variety of rehabilitation services, which include home teaching, mobility services, and supportive services.

The Deaf

1. One-third of all deaf people have other disabilities besides deafness. Prevalence of deafness is more than three times as high in persons aged 65 and over then in all age groups combined.

2. The tested educational achievement of deaf persons lags far behind that of nondeaf persons, although the average deaf adult lages only one grade behind nondeaf persons. Similarly, deaf persons tend to be employed in positions significantly below their intelligence, skills, and education. The average income of the employed deaf is far below the national average. Nonwhite deaf males have five times the unemployment rates of white deaf males.

Provision of Rehabilitation Services

Survey of Providers

1. A clear majority of respondents to the Provider Survey considered it appropriate for the VR program both to focus the major portion of its attention on serving the most severely handicapped and to serve as the vehicle for providing rehabilitation services for independent living. Furthermore, two-thirds of the respondents believed themselves capable of serving the more severely handicapped, although they felt they needed more funds and staff to accomplish this objectives.

2. To facilitate the serving of severely handicapped through VR, a number of policies were favored such as: (1) an intensive training program for counselors; (2) a reduction of caseload size; and (3) development of a weighted case closure system.

Rehabilitation Facilities and Workshops

1. Rehabilitation facilities play a key role in service provision and evaluation of severely handicapped individuals. Furthermore, workshops are often the major source of skill training and, too often, the only source of jobs.

2. Providers, individuals, and organizations all agree that an increased number of rehabilitation facilities and added support to facilities

are essential to the provision of service to all of the severely handicapped who could be rehabilitated.

3. The development of a subsidy program to both workshops and to individuals in a workshop setting should be considered. The RSA-funded workshop study should provide greater insight into this area.

Technology

1. The basic problem addressed by technology is whether a loss of function suffered by an impaired organism can be replaced by artificial means. The Rehabilitation Engineering program of RSA contains great promise for significant breakthroughs and should be expanded.

2. In P.L.93-112, provision is made for funding the development and/or modification of devices which are not commercially feasible for production, to meet the needs of various disability groups. However, money has not been appropriated for this purpose.

3. A serious effort should be made both to extend the areas in which rehabilitation research is now being conducted and to manufacture and to disseminate devices for the disabled. Consumer involvement should be included.

4. It is also important to consider the training requirements inherent in dissemination both for professionals and the disabled users.

Benefit/Cost Analysis

1. Many types of analyses can be used to establish the value of certain program expenditures. Such analyses often focus on the "benefits" and "costs" of the given program, although they vary greatly in utility, assumptions, and conclusions. Vocational Rehabilitation is one of the few social programs for which benefit/cost analyses have been made. However, we wish to express reservations about the confidence that can be placed in these findings. While the technical aspects of the work have been very acceptable, the basic data have

simply not been available, and this has necessitated innumerable assumptions. If one wishes to accept these assumptions, the analysis conducted as part of this study shows that the benefit/cost ratio of serving the severe handicapped accepted by VR is less than that of the nonseverely handicapped accepted by VR, but is still high (9.1).

2. The limitations of the benefit/cost caluclations have not generally been recognized by advocates and critics of the Vocational Rehabilitation program. If Congress and the Department of Health, Education, and Welfare want to use benefit/cost analyses as important inputs to setting appropriations priorities, then addition data necessary to develop accurate benefit/cost estimates must be collected. Alternatively, if Congress desires to set priorities on the basis of other considerations besides economic efficiency (i.e., if Congress desires to place highest priority on the severely handicapped because of their greater need for services), then more comprehensive data are not as vital.

Other Programs

1. In the course of work on other programs for the severely handicapped, we found that no comprehensive review of the Federal programs and policies affecting the disabled existed before the recently completed effort by the Office of Handicapped Individuals.

2. While few data exist, it is clear that programs are fractionated, sometimes in competition with one another, and often inconsistent within themselves. The major problems are that programs: are inequitable, contain gaps in services, suffer from inadequate control, and are operated with insufficient knowledge and resources.

3. Our rough estimate is that $21.5 billion was spent to assist the 10 to 11 million severely disabled, or about $2,000 per severely disabled

individual in FY 1973, the last year for which complete expenditure data were available. VR expended just under $0.4 billion, or about 2 percent of the total budget for this group.

4. Coordination of such programs will be difficult because of their differing purposes and program structures.

Many programs contain severe disincentives to the vocational rehabilitation of the severely handicapped because the programs are predicated on assumptions of labor force retirement. Since these income maintenance programs bestow needed cash on the severely handicapped, ususally have concomitant medical benefits, and open eligibility to other programs as well, the cumulative benefits often require very high wage options before persons have incentives to show they are capable of labor force participation. We do not suggest persons are malignering, but that motivation is often necessary to overcome a handicap and without it, persons will not strive. Legislative changes would be required to allow these programs to be based on severity alone and not on labor force withdrawal, so that the severely handicapped could work without significant penalties in lost benefits. Such changes would permit greater coordination of these programs with VR.

Options

Programmatic Options

1. A strong case can be made that we have the technical expertise to provide services not currently being provided widely or equitably to a large number of the severely handicapped. Thus, the technology for service provision is known, many of the services could be feasibly delivered, and most recipients would benefit from the receipt of such services. Expansion of VR is largely a function of the resources available and the nature of the labor market. These are decisions for the Congress and the Administration, primarily with respect to investments in human capital.

The most crucial decision area is in regard to development of an independent living program. The logical options for this are summarized below.

1. Have no ILR program
2. Expand use of Extended Evaluation.
3. Add ILR program.
   - A. In non-VR agency
   - B. In separate, but VR-related, agency
   - C. In VR
     1. Residual to VR
     2. Separate from VR
     3. Single program with VR

If the decision is no ILR program, what does it mean? It means that the population at risk is about where it is now; that is, the services will or will not be there depending upon whether individuals can find them, develop eligibility, and do their own advocacy. People in nursing homes or people rejected for severity will remain as they are now. This does not mean that all severely handicapped will be unserved, but that they will be served by the system that currently exists.

One way to better serve the severely handicapped without setting up a new program or without simply retaining the status quo is to modify the existing program so that service provision which may end short of a vocational placement is expanded. There are State directors of VR who feel that they are achieving ILR through their use of Extended Evaluation and through homemaker rehabilitation. The expectations, however, in these cases are that these must be vocational in nature, and these outcomes are treated as "least choice." If the Congress and Administration feel that the self-care, homemaking outcome is equally as important as job placement, then expansion of the conditions under which this outcome is appropriate would, in effect, expand the services and number of clients with severe handicaps served without vocational objectives. This outcome could even be described as an outcome appropriate to persons who are employed but need the additional assistance.

One of the options specified is for a non-public agency to run the ILR program with Federal grants and supervision. The idea of the voluntary sector providing publicly funded services may seem novel, but such arrangements have existed for many years. Sheltered workshops, rehabilitation facilities, and voluntary organizations such as Easter Seals, cerebral palsy, and epilepsy organizations have been providing services for the most severely handicapped for years, often with grants, purchase of service contracts, or other arrangements with public programs.

Another possibility is consumer-run self-help organizations to fill the present gaps in the disability service delivery system. For example, the Center for Independent Living in Berkeley, California is staffed almost entirely by people with severe disabilities. They set up and provide services themselves, since for many of the severely handicapped the services required are not in the domain of any given agency--instruction in home

remodeling, assurance of equipment repair, or an inventory of experienced attendants, for example.

Of course, the ILR could be set up within the VR agency, with the expectation that the organizational relationships within the agency could be worked out. The options are most succinctly described by looking at the decisions which must be made regarding client selection and flow.

One approach would have the agency screen clients for vocational potential. Clients would be selected as at present. Only those clients failing or rejected due to severity would then get ILR services as necessary.

Another approach within the VR agency would be to set up totally distinct units, each having its own manpower and budget, and to establish internal agency referral procedures. This option may be so rigid as to constitute an internal agency option much like the independent agency related to VR described above.

A third approach would be to have no distinctions between the programs. Any handicapped persons arriving at intake will be provided the services from which they can benefit, for as long as they can benefit, regardless of outcome. Thus, there could be few "unsuccessful" outcomes, since most people would be rehabilitated to a vocation or to independent living.

Lastly, the ILR program could, in effect, be the evaluation arm and service provider, as in extended evaluation. All handicapped persons wishing services would be first seen by the ILR program, which refers them to the VR program only after their ILR needs have been met. This should reduce the number of persons not rehabilitated in the VR program, because most of the people in VR will have had most of their needs met, except vocational.

Operational Definitions of Severity

1. The current RSA definition of the severely handicapped has a number of advantages and disadvantages. The major advantages are that it is

well known by people in the field, and it provides flexibility for the counselor who may consider such factors as the client's transportation difficulties. On the other hand, it continues the practice of "labeling," furthering the stereotyping of people who are severely handicapped. More importantly, there is only a minimal relationship between diagnostic labels and severity.

2. The extended RSA guideline alternatives have the same advantages as the current RSA definition but with somewhat finer disability discriminations.

3. A method which focuses on measuring functional limitations appears to have the greatest number of advantages since it is reliable, valid, and relatively easy to administer.

4. A method that would consider all aspects of a person's handicap would have a major advantage, in that it would take into account such factors as motivation, family support, attitude, etc. On the other hand, it would be difficult to develop a valid, reliable measure of this sort which predicts vocational performance.

5. In light of the wide discrepancy among States in the rate at which they report serving severely handicapped people, some objective instrument for establishing severity appears highly desirable.

Financial Options

1. Many possibilities exist for the design and financing of rehabilitation programs. Many of these options can be combined and possible combinations are innumerable. Financing was discussed along three dimensions: 1) Federal participation; 2) funding through programs; and 3) client cost sharing. Options along the first dimension include: full Federal financing, special revenue sharing and joint funding between Federal, State, and local levels of government.

2. A major argument in favor of full Federal funding is that if states have a great degree of control, wide variations between State programs (and therefore inequities) may result, in both population served and services provided.

3. Under a special revenue sharing plan a VR program would have a given Federal allotment, funds being dispersed to States and/or local governments by means of an allocation formula determined by population, target population, State income and/or other State characteristics. Use of a formula which takes into account different State and local needs allows the dispersal of the most resources to those States which are in greatest need of assistance in achieving national goals. It also preserves the role of the Federal Government as a redistributor of income. On the other hand, it can be argued that when localties are allowed such broad discretion in the use of funds as would occur with special revenue sharing, there is no certainty that all would be able to achieve national goals in rehabilitation without specific direction or that, without monitoring of funds, misuse would not occur.

4. Programs which are federally authorized but jointly funded by State (and sometimes local) governments generally allow greater variation among States in terms of program design and administration and reduce the financial burden on the Federal Government. Arrangements under which States contribute to program financing may involve (1) an allocation formula to determine the Federal contribution to individual States based on such State characteristics as total population, target population, and income, etc., and/or (2) a matching ratio that fixes the number of Federal dollars for each dollar contributed by a State towards a particular program, possibly variable by State and possibly subject to a maximum determined by an allocation formula.

5. It should also be realized that programs can be funded from more than one source. There are many examples of joint funding: Medicaid pays the costs of premiums, deductibles, and co-insurance of the poor who are eligible to participate in the Medicare program in some States; VR services for certain Disability Insurance recipients are paid by DI Trust Fund monies; and VR agencies are reimbursed at 100 percent of the costs of rehabilitation for certain blind and disabled recipients of Supplemental Security Income. In addition, VR agencies are required to make maximum use of similar benefits provided by other programs. Procedures should be developed by which the rehabilitation agency could pay vendors for needed services through a revolving fund. VR would then be reimbursed from the programs which finances the services such as Medicaid.

KEY POLICY INTERPRETATIONS

In this section we present only some of the key findings of the study and make some observations on the implications we see for the current program and for the deliberations over an independent living program. We make the assumption that only a modest increase in the level of direct funding to Rehabilitation is likely to be available for an expansion of services. Obviously, if this assumption proves to be in error, the judgments reflected below would have to be adjusted accordingly.

Definition of Eligible Population

While a great proportion of the providers of rehabilitation services indicated that the definition used in the Vocational Rehabilitation Act is adequate for the purpose of defining severity, we feel that some more objective instrument or means should be developed so that applicants and evaluators will have objective criteria to judge the agency actions. We have indicated a number of options on these approaches, but we feel that further research is required to develop a screening instrument consistent with legislative intent to serve the severely handicapped. For the VR program, we feel that the primary source of variation in selection criteria should be the availability of local rehabilitation resources such as workshops or medical rehabilitation centers. Save for these, any severely handicapped person in any State should have the right to expect approximately equal probability of acceptance. We recognize that actual closures into the competitive labor market will vary depending on labor market conditions.

Concomitant with this we would suggest more stringent quality control, especially on cases closed for severity. We propose making a distinction in the VR reporting system which would allow "difficulty of placement" as a legitimate closure code. Such a closure code would more accurately reflect local labor market considerations. While one does not want VR to waste funds on futile

efforts to place persons for whom the labor market will not make places, one also wishes to distinguish clearly between those reasons based on severity and those based on factors such as age and education combined with a disability.

One method of developing cost estimates would be to consider a program to serve the 18-64 age group of 68,000 closed in 1972 for severity. Making modest assumptions of care needs--two round trips per week in a taxi, 1 hour per day for an attendant, 1 hour per week of a home health aide, 1 meal per day brought into the home, 4 hours of personal and adjustive counseling per year and (for 10 percent) $1,000 toward college tuition--the cost of such a program would be $115.1 million. The table below summarizes these estimates.

Table 1

Annual Cost Estimates of Modest Program
to Serve the Handicapped Rejected by VR

Service	Unit Cost	Units	Persons	Costs ($millions)
1. Homemaker/attendant	$ 3.00 per hour	365	37,400[1]	41.0
2. Home health	$11.00 per hour	52	27,900[2]	16.0
3. Meals on wheels	$ 1.55 per meal	365	37,400[1]	21.2
4. Transportation/taxi	$ 6.00 per round trip	104	37,400[1]	23.3
5. Counseling	$25.00 per hour	4	68,000	6.8
6. Education	$1,000.00		6,800	6.8
TOTAL				115.1

1. 55 percent of our sample were dependent, a proportion used here.
2. 41 percent were moderately to totally dependent.

An alternative approach is to ask what the authorization of $80 million would have purchased, this being the high-level authorization had independent living rehabilitation become operated. Average Federal shares of counselor time in direct salary and fringe benefits, not counting office space and support costs, for FY 1973 was approximately $20,000 per counselor year. Diagnosis, evaluation and restoration ran about $600 per client. If each counselor did nothing but serve 100 clients per year for these two services, $80 million would permit services to 100,000 clients.

Put another way, to cover costs of 100 clients per year per counselor (or a total counselor time per client of 20 hours), diagnosis and evaluation, restoration at costs comparable to the average caseload, $80 million would have paid enough to cover the 68,000 persons rejected for severity reasons and to send about 13,300 of them to rehabilitation centers or workshops for about 2 months each.

Transportation

Greater emphasis on barrier-free public transportation, including curb cuts on the way to it and other efforts to enhance mobility would be a major assist for many of the severely handicapped.

While we do not expect the rehabilitation agencies to start major alternative transportation systems, we feel that the agencies can make greater efforts as advocates for accessible transportation and in providing support for paratransit systems to be set up and operated by the handicapped themselves until barrier free systems exist.

Employment and Labor Force Participation

The prospect for employment for the majority of the most severely handicapped in the competitive labor market under today's conditions and without major subsidies to either the employer or employee seems dismal. Affirmative Action efforts will probably extend opportunities somewhat to the less severely disabled. Without

major legislative changes, the present employer attitudes, the effect of perceived and actual increased insurance premium costs (an area worthy of greater investigation in itself), job requirements for flexibility of schedules, and modifications to places of employment, all suggest that labor force participation is a faint hope for all but a few of the severely handicapped. Legislative changes could include the elaboration of the authority in the Vocational Rehabilitation Act for new careers into a public employment program for the severely disabled, with funds for ongoing support of positions. In addition, the number of workshops and facilities should be expanded, as an estimated 1,000,000 could benefit from such placements.

Long-Term Care

If there is one priority area in which rehabilitation might make substantial contributions to both public policy and the severely handicapped, it is in working with clients in nursing homes and long-term care facilities. It would be desirable to work out more of the issues in demonstrations before moving ahead on legislation for Independent Living, but on the face it appears a very valid concept. Long-term care vendors, especially those in the for-profit sector will have few incentives for permitting rehabilitation to occur in their facilities. The most rehabilitatable individuals are probably those who require the least care and, hence, are most profitable. Turnover of beds is itself a cost to the vendor. Reluctance to easily cede profit is understandable. Similarly rehabilitative goals for this population are difficult to achieve because of a lack of community resources. Group residence facilities and other supportive settings which allow more independent living than nursing homes are not widely available.

Health Coverage

Our investigation was not able to assess the extent to which all of the severely handicapped have health care coverage. Since about 67 percent have Supplemental Security Income (SSI) and Disability Insurance (DI) benefits, they

would have some coverage under Medicaid or Medicare. Another group would have Veterans Administration benefits. The CMRC clients had their services covered by third party vendors in 97 percent of the cases. The VR population reported a high degree of coverage as well. Thus the coverage for acute health care seems less problematic than the coverage for certain services. For example, after the initial device is supplied, the cost of repairs or replacements are largely borne by the individual. Coverage for items such as attendant care or home health aides even in the public programs is very limited.

We would suggest further investigation of the potential costs of separating health care coverage from income maintenance, extension of health coverage to all severely handicapped persons regardless of employment or income (but with reasonable cost-sharing provisions), and expanded scope of services covered to include ongoing needs for equipment maintenance and replacement, attendant care, interpreters, readers, etc. At present, good data on utilization patterns and cost factors are unavailable.

The objective of separation of health coverage from income maintenance is to reduce loss of health benefits for those who wish to work. The fear of being burdened with major costs of care discourages many from seeking the highest level of social and vocational functioning of which they are capable. Coverage of the acute and ongoing medical, home care, and equipment needs of this group seems warranted without regard to labor force participation. We feel that the coverage should not be through the rehabilitation program, since the needs and purposes of such coverage are broader and most consumers of these services should be reasonably competent to procure their own. Rehabilitation should, however, be able to counsel those with difficulties. Similarly, we feel that existing public programs financing health care services should be required to take the burden of costs for such care off the rehabilitation program. If the medical care financing programs were broad enough and responsive enough to cover the necessary services promptly and at reimbursement rates that assured quality

care from vendors, then the rehabilitation role should focus primarily on case management, monitoring, quality control and other activities. The substantial funds available to provide restoration could then be placed back into other rehabilitation services.

As a minimal proposal we would suggest that Congress eliminate the rule requiring 2 years of receipt of Disability Insurance Benefits before persons are eligible for Medicare coverage. It is an unjustifiable barrier to many who might like to be vocationally rehabilitated.

Income Maintenance

Small legislative changes in SSI and DI could make big differences to the severely handicapped and to their motivation for rehabilitation. We are unable at this time to estimate the likely impact on caseload and expenditures of some of these suggestions, but given the high proportion of severely handicapped already covered (67 percent) we feel that a significant increase in the billions currently expended is not likely. The results, however, in encouraging the severely handicapped to attempt greater self-realization would, we think, be commensurate with the costs. We would propose that the definition of disability used for eligibility in SSI and DI be based entirely on the severity of the disability as measured by some objective instrument and earnings history to distinguish between the programs. This instrument should be scaled at the level of severity of the current SSI-DI caseload. Then reference to Substantial Gainful Activity should be dropped and instead a provision for exemption of reasonable costs of employment and the present SSI 50 percent tax rate on earnings be substituted. This would have to parallel the separation of health benefits from eligibility for income maintenance, since even working without income maintenance may cause severe dislocation if health coverage is also lost.

Altering the income maintenance programs in this way would offer several advantages to rehabilitation as well as to the severely handicapped. More

persons would have some incentives to try to work to improve their incomes. This should permit rehabilitation to receive more motivated clients. Secondly, this allows individuals with some income to work and should reduce the amount of maintenance expended by VR itself, again permitting greater investment in other services. Given the limited demand for severely handicapped labor, we cannot presently estimate the behavioral effects (which may be minimal and result in minimal costs), but we suspect the morale effects will be substantial.

Coordination of HEW Programs

The problem of coordinating HEW programs for the handicapped is considerable. These programs have differing purposes, objectives, and target groups. Some are federally administered, some State administered, and some administered at the local level. Initiatives designed to pull such programs together, such as Services Integration and the Allied Services proposal have so far reported limited, if any, success. Within HEW itself are the bureaucratic realities of the differences in size and influence of the Social Security Administration relative to the office of Handicapped Individuals and RSA. We are growingly convinced that if Congress seriously expects coordination then it will itself have to make major efforts to reconcile differing legislative purposes and to mandate more authority to the Office of Handicapped Individuals in order to gain the full cooperation and participation of the various agencies.

Consumer Involvement

While there are considerable problems in defining who is a consumer and who really speaks for whom, we were struck throughout this study by the growing number of consumer-run organizations and the growing awareness and advocacy of many of the individuals.

Rehabilitation needs to make greater use of these individuals and organizations. It is they, after all, whose lives are affected for good or ill, who can say what is in their interests and what is not. Certainly this is a problem

for many professionals, even in rehabilitation, to accept an ungrateful or a critical client. But we feel that by utilizing consumers in rehabilitation, a more effective rehabilitation program can be established, especially in the area of coordination of services. We have heard of a case, for example, when a client would not sign off on his Individualized Written Plan because he thought the workshop was overcharging for the program that he was to enter. Consumers are uniquely able to make this type of assessment.

Financing

From the point of view of the VR program itself we are concerned that the number of expectations placed on the program far exceed the resources available to meet them. Rehabilitation budgets for the past few years have been virtually constant, without considering the effect of inflation. The Congress and the Administration have made little in the way of unequivocal statements that they expect the natural concomitant of this fiscal constraint and the efforts to move toward the more severely disabled to result in fewer rehabilitations, higher cost rehabilitations, and greater incident of closures which are either unsuccessful or in non-wage occupations. Such a signal would assure the program managers in the States and probably make the job of facing the State legislatures for the State share of rehabilitation funds somewhat easier.

If the Congress is desirous of an independent living program we would think authorization levels far in excess of those included in the previous bills would be called for, if only to cover those persons presently closed for severity. We would think that an authorization of 30 to 80 million dollars would be most usefully spent on a project grant program modeled after the Innovation and Expansion Grant Authority which would establish a series of projects to investigate various approaches, assess the most effective and efficient means for providing such services, and work out the optimal interrelationships with other delivery systems before a large formula grant program is introduced.

We would think that much of the financing of both VR and an ILR program should be accomplished through the general health and income maintenance programs as pointed out previously.

Lastly, in financing of a formula grant program of independent living, some consideration should be given to the possibility of client cost sharing since some services provided under a program of this type might include those normally provided by the individual--meal preparation, homemaking, recreational activities, etc. Client cost sharing should include (1) payments associated with inclusion in the program and (2) payments associated with use of the program's care benefits.

Independent Living Rehabilitation or Not

As contractors we can only suggest that the need for independent living rehabilitation is there and that the rehabilitation system as it currently exists could provide such services as may be authorized. We were struck, however, by the potential cost of such a program and the minimal authorizations proposed in the previous bills. Given the focus in VR on the severely disabled, we would suggest not beginning a formula grant program of independent living until a minimum of $150 million per year can be assured to provide coverage just for those currently in contact with VR and not served due to severity. Any lesser funds would be well spent in VR as it presently is structured. Congressional interest in an independent living program might be effectively expressed through first mounting demonstration projects to work out the service delivery and coordination issues until such time as funding for both VR and ILR is available.

The way to most easily accommodate a very modest program of independent living is through expansion of extended evaluation. One small step would be to have all persons thought to be infeasible due to the severity of their impairment go through a full program of such services. We would exclude those who are not actually severely handicapped but whose closure is based on other characteristics which

make competitive placement difficult, such as age or inadequate education or skills. Most of these persons seem to have few limitations in self-care and mobility.

When so limiting the program, it is important to also establish new measures of success. At present a client closed from extended evaluation without vocational rehabilitation is counted as a non-success despite the benefit received from services. Certainly measurable, successful independent living outcomes can be defined: no longer needs attendant, can now travel alone, reduced need for assistance in homemaking, and so forth.

If the ILR program were limited to those severely handicapped who get to a VR Agency but who cannot be vocationally rehabilitated, it is possible to avoid many programmatic issues concerning which services to provide, how to interface with other delivery programs and, at the same time, recognize the limitations of resources in dollars, facilities, and manpower. For 1972 we found 68,000 VR clients closed for severity. Our survey of VR clients showed 41 percent had Barthel scores reflecting moderate to severe dependency due to their impairment. If this applied across the board, there would have been about 27,000 clients with limitations. For $80 million, about $3,000 per client would be available for counselor and case service costs, as well as administrative costs.

If any initiative is to be mounted in new areas, we would propose it be in the rehabilitation of persons in nursing homes and related long-term care facilities. While many persons in these institutions need some level of care and supervision, there are some who could be rehabilitated to their homes or more congenial community settings if they got some rehabilitation services. Movement to these settings could reduce outlays in Medicaid and Medicare for these individuals and offset costs of rehabilitation services. Demonstrations of the possibilities of such an approach prior to legislation would be desirable, but if the reform of health and long-term care programs proceeds rapidly, we

feel the State-Federal rehabilitation program and/or CMRCs should be written in, based on the face validity of the accomplishments in the field.

Summing Up

When we began this study VR loomed large. At the end we found that it accounted for about 2 percent of Federal expenditures on the severely disabled. While its influence far outstrips that modest proportion, we wondered at the expectations people placed on the program without the corresponding willingness to provide the resources.

Any exercise which approaches a population from the perspective of "needs" is very likely not only to find needs but also to find the associated costs of meeting those needs to be very expensive. To have a comprehensive program for the severely disabled that comes anywhere near to living up to its name and expectations would cost billions. The Congressional authorizations, much less appropriations, belie the impulse. The $30 million first-year authorization could be spent entirely on demonstration projects. The Nixon Administration was, perhaps, more honest in saying it chose not to put up the resources, but it failed in dealing with the consequences.

When Congress turns to VR to deal with the more severely handicapped, several things happen. Whatever the merit of digging into the pool of more severely handicapped, some of the traditional clients must be abandoned. These are clients whom many consider quite worthy of services. But to serve the more severe, given no additional resources, means something or someone has to go. The next thing that happens is that the risk of failure mounts, not so much because VR does not know how to rehabilitate but that the labor market does not easily accommodate the more severely handicapped. The number of closures drop. No matter that Congress may not mind, nor that good is done anyway. While Congress may be willing to watch the number of rehabilitations drop with some satisfaction that the more severely handicapped are better served, there is

little to indicate that State legislatures and governors are so sanguine. And it is a State-Federal program. Indeed, there is little to say that the Administration is so inclined. When rehabilitation declined in the first part of the year, the Secretary of HEW wanted to know why.

No one can fault the desire to actualize the potential of every disabled person. However, the realities of resource constraints require responsible public officials both in Congress and the Administration to make the hard choices and not make grand pronouncements of humanitarian concern, while leaving it to the local counselor to turn away the specific individual at the door.

Much technical knowledge exists to allow the severely handicapped to realize their potential. Design of a goal oriented program and significant financial commitment is required. This commitment must be undertaken if the promise of providing comprehensive services is to be fulfilled.